

RESEARCH ARTICLE

Dementia patient and caregiver relevant outcomes currently being reported by adult day service centers in the United States

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Abstract

Background: Approximately one third of adults in adult day services (ADS) centers have Alzheimer's disease (AD) and AD-related dementias (ADRD). Understanding of the impact and effectiveness of ADS on persons living with dementia (PLWD) is limited by a lack of patient and caregiver relevant outcomes (PCRO) data. We identified PCROs collected at ADS sites in states that mandate serial data collection and examined the degree to which these data align with established Dementia Care Practice Recommendations (DCPR) and PCROs used in other areas of long-term care.

Methods: We conducted an item analysis of regulatory forms used by ADS. Consistent with the methodology used by the Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory for PCROs collected in other long-term care settings, we created a matrix informed by DCPR. We matched each item in regulatory forms reflecting a PCRO to one of the seven DCPR domains as well as to the 53 PCROs from other long-term care sectors.

Results: Ten states routinely collect outcome data in ADS. Among these, 80% assess cognitive function. All 10 states capture PLWD's ability to complete activities of daily living. Presence and frequency of behavioral symptoms were collected by 80% of states. Very few or, in some cases, none of the 10 states, collected PCROs related to care planning and coordination, education, social support, and/or family caregiver burden and support.

Discussion: Lack of standardized collection of PCROs hampers researchers' understanding of ADS. The vast majority of PCROs collected center on participants' physical health; conversely, data on socialization, social support, and caregiver well-being, which are purportedly the most impactful services offered by ADS centers, are rarely collected. ADS would be well served to focus on these outcome domains as the resulting data could paint a more complete picture of the holistic impact of ADS on PLWD and their caregivers.

KEYWORDS

adult day services, Alzheimer's disease, dementia, patient and caregiver relevant outcomes

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1 | BACKGROUND

Dementia is a syndrome that encompasses loss of memory, language, problem solving, and ability to think to such an extent that it interferes with a person's daily life and limits their ability to function independently.¹ The number of people living with dementia (PLWD) is expected to reach 132 million by 2050.² Dementia has profound physical, psychological, social, and economic impacts—not only for PLWD, but also for their families who must balance caregiving with other demands.³ In the absence of a cure for dementia, treatment goals may include maintaining quality of life, maximizing physical function, providing social engagement, and fostering a safe environment.⁴

1. **Systematic Review:** Several leading researchers focused on adult day services (ADS) have called for systematizing collection of patient and caregiver relevant outcomes (PCROs) in ADS to understand their impact on persons living with dementia (PLWD). The relevant citations are appropriately cited.
2. **Interpretation:** We explored how ADS could pragmatically leverage existing clinical and administrative data—namely PCROs that sites are already collecting for regulatory purposes—to measure their impact on the well-being of PLWD and their caregivers. Among the 10 states that mandate data collection in ADS, PCROs are largely focused on physical health, and do not assess impact of ADS on care planning, emotional support, or communication.
3. **Future Directions:** These findings synthesized evidence on collection of PCROs in ADS and suggest opportunities for ADS to measure and report on PCROs that are well within the reach of their services, such as emotional support and advanced care planning.
4. Only one in five states mandate the collection of outcome data in adult day services (ADS).
5. Data collection in ADS is primarily focused on physical outcomes.
6. Care planning, emotional support, communication, and education are rarely assessed.
7. Opportunities exist for ADS to report on patient and caregiver relevant outcomes that elevate dementia care standards.

In the last two decades, adult day services (ADS) have gained attention for their ability to provide respite to family members and enable cognitively and/or functionally impaired older adults to remain in their communities.⁵ ADS is “a system of professionally delivered, integrated, home and community-based, therapeutic, social and health-related services provided to individuals to sustain living within the community.”⁶ In 2018, an estimated 251,100 Americans participated in ADS on a daily basis. Of these individuals, 28% had a documented diagnosis of Alzheimer's disease (AD) and AD-related dementias (ADRD).⁷ ADS clients benefit from a wide array of therapies and assistance, including social activity, support with activities of daily living (ADLs), meals, exercise, and more.⁶

The care delivered in ADS aligns with the general clinical approach to managing care of PLWD; it is primarily directed at symptom management and reducing caregiver strain. However, the impact and

effectiveness of ADS on the health of PLWD and their caregivers has yet to be conclusively established. A review of the literature from 2000 to 2011 suggested that participation in ADS may have positive impacts on participants' psychosocial well-being, but the success of ADS in addressing other important participant outcomes remained unclear.⁸ The dismay communicated by participants, caregivers, and staff over the shutdown of most ADS centers during the COVID-19 pandemic provides additional anecdotal support for the perceived value of ADS for participants and their caregivers.^{9,10}

A primary barrier to understanding the impact and effectiveness of ADS on the well-being of PLWD and their caregivers is the fact that patient-level outcomes are infrequently collected in any standardized fashion across ADS sites. In early 2020, researchers distributed a survey to the 3768 members of the National Adult Day Services Association (NADSA) LISTSERV to discern what data are currently being collected by ADS centers, as well as to learn more about the data collection requirements in each state. An analysis of survey results revealed that only 32% of respondents reported regularly obtaining client outcome data for research purposes.¹¹

Several leading researchers focused on ADS have called for the implementation of standardized process and outcome measures across ADS.^{12–14} They have specifically called for the collection of patient and caregiver relevant outcomes (PCROs) that reflect the lived experience and priorities of people living with dementia (PLWD) and their caregivers.¹⁵ Recognizing the numerous demands facing ADS staff, researchers have emphasized the importance of ease of administration as well as time- and cost-effectiveness when it comes to instituting any measures. Our goal was to understand how ADS sites could pragmatically leverage existing clinical and administrative data—namely PCROs that sites are already collecting for regulatory purposes—to measure their impact on the well-being of PLWD and their caregivers. The purpose of this paper was to (1) identify data points currently being collected at ADS sites in states that have regulatory mandates on data collection within ADS and (2) examine the degree to which these measures align with Dementia Care Practice Recommendations (DCPR) and PCROs used in other areas of long-term care, such as skilled nursing facilities.

2 | CONCEPTUAL FRAMEWORK

In 2018, the Alzheimer's Association released its DCPR.¹⁶ The DCPR were developed through review of existing evidence and in collaboration with experts in the field, and are designed to be used in a variety of settings throughout disease progression.⁴ At the heart of the DCPR is a focus on person-centered care, a philosophical approach that emphasizes the individuality, humanity, and rights of PLWD. The DCPR are broken into eight primary domains: (1) detection and diagnosis; (2) ongoing care for dementia-related behaviors and ADLs; (3) assessment and care planning; (4) medical management; (5) information, education, and support; (6) supportive and therapeutic environment; (7) transition and coordination of services; and (8) staffing.⁴

Under the detection and diagnosis domain are recommendations for increasing education on brain health, as well as person-centered ways to facilitate diagnosis of dementia and understanding of this diagnosis for PLWD.⁴ The ongoing care for dementia-related behaviors and ADLs domain encourages care providers to understand the environment in which behaviors occur, and to provide nonpharmacological support tailored to the PLWD's needs. When supporting PLWD in ADLs, this domain states that dignity, respect, and choice must be prioritized.⁴ Providers are encouraged to work collaboratively with PLWD to develop strategies that allow PLWD to live fully under the assessment and care planning domain. This domain also includes suggestions for advanced care planning.⁴ The medical management domain encourages PLWD and their caregivers, doctors, and nonmedical support personnel to work together to comprehensively address the PLWD's medical needs. The information, education, and support domain includes an array of evidence-based recommendations for sharing information with PLWD and their families about dementia, including early in the disease and during times of transition.⁴ Suggestions to increase comfort, dignity, safety, and engagement in the care community are provided under the supportive and therapeutic environment domain, while the transition and coordination of services domain addresses strategies to smooth transitions in care for PLWD.⁴ Finally, the staffing domain explains best practices for encouraging person-centered service delivery by the dementia workforce.⁴

Since their establishment, the DCPR have played an important role in meeting the urgent public health needs of PLWD. The PCRO core within the National Institute on Aging (NIA)'s Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory developed a searchable library of AD/ADRD PCROs across long-term care settings, aligning the items in this database with the DCPR.¹⁵ Consistent with the approach used by researchers at the NIA IMPACT Collaboratory, we used the DCPR as a framework for analyzing data collection in ADS. In this study, we organize PCROs collected by ADS in states with mandatory requirements for data collection within a matrix informed by the eight DCPR domains.

3 | METHODS

To identify data points currently being collected at ADS sites we had to first identify states that require ADS sites to report participant level data and the regulatory forms that are used to collect these data. To do this, we revisited results from our 2020 national survey of adult day service providers conducted in conjunction with NADSA.¹¹ We examined answers to the survey questions listed in Table 1.

We analyzed the open-ended responses to identify states that require data collection and/or the regulatory document/form that is used to capture the data. We then did cursory online searches and searched state-run websites for the relevant regulatory forms. If we were unable to locate the forms through online search, we reached out to contacts at various state ADS associations to obtain them.

Upon obtaining the regulatory forms, we did an item analysis of each document. We matched each item reflecting a PCRO within the

form to both the DCPR domains as well as to the 53 PCROs from other long-term care sectors found within the PCRO library. This approach, which aligns with that used by the NIA IMPACT Collaboratory for their PCRO library, allowed us to examine the degree to which these measures align with PCROs used in other areas of long-term care.

4 | RESULTS

Ten states (Oklahoma, Kentucky, Florida, Maryland, California, Virginia, Texas, Nevada, North Carolina, and New York) required ADS sites to report participant-level data. Table 2 presents domains reported by ADS from these 10 states. Generally speaking, among the total of 53 items within the library reflecting PCROs collected in other areas of long-term care, Oklahoma recorded and reported the greatest number of PCROs relevant to PLWD ($N = 37$), followed by New York ($N = 34$), Kentucky ($N = 32$), Florida ($N = 31$), Maryland ($N = 26$), California ($N = 23$), Virginia ($N = 22$), North Carolina ($N = 19$), Texas ($N = 14$), and the least was Nevada ($N = 11$).

The detection and diagnosis domain was used to evaluate PLWD's cognitive function. Eighty percent of states included cognitive function in their report forms, with most states using non-standardized scales. For example, Virginia included some specific examples as references for the clinician's evaluation (e.g., "please tell me your full name" for person orientation or "spell the word 'WORLD'" for attention/concentration), while some states only asked the clinician to report whether or not the client had some form of cognitive dysfunction (e.g., memory loss).

The ongoing care for dementia-related behaviors and ADLs domain refers to consistent care for behavioral and psychological symptoms of dementia (dementia-related behaviors), and support for ADLs. The subdomain of ADLs had the most commonly reported items, with all states capturing PLWD's ability to complete ADLs in their report forms. Data on bathing and dressing were collected by ten states; ambulation, toileting, medication management, housework by nine states; transferring/transportation, money management, meal preparation, feeding/eating, phone use by seven states; hygiene, shopping by six states; bed mobility by two states; and accessing resources by only one state. Additionally, seven states collected data on hearing and vision deficits and four states collected data on the use of assistive devices (e.g., wheelchair, walker, gait belt, crutches), as part of ADL assessments in PLWD. The subdomain of dementia-related behaviors was also commonly reported by ADS, capturing the presence of behavioral and psychological symptoms of dementia. The presence and frequency of behavior symptoms and wandering were reported by 80% of states. Presence of restlessness or agitation was reported by 50% of states, and presence of anxiety, sadness, or presence of depression were reported by 60% of states. Potential indicators of psychosis were reported by 40% of states. The presence of dementia-related behavioral and psychological symptoms was assessed using clinician (e.g., registered nurse, social worker), judgment rather than a formal instrument.

TABLE 1 Relevant survey responses to identify states currently collecting data

Survey question	Response
Do you screen your participants for...	
57. Their ability to carry out activities of daily living	Yes/No/I am not sure
60. Loneliness	Yes/No/I am not sure
66. Their ability to carry out independent activities of daily living	Yes/No/I am not sure
68. Cognitive impairment	Yes/No/I am not sure
74. Depression or depressive symptoms	Yes/No/I am not sure
82. Substance use disorders	Yes/No/I am not sure
91. Quality of life	Yes/No/I am not sure
If yes [to 57, 60, 66, 68, 74, 82, or 91], are you required to collect this information by the state you operate ADS in?	Yes/No
If yes [to 57, 60, 66, 68, 74, 82, or 91], do you use an evidence-based tool or state-required form to conduct this screening?	Yes/No
If yes, please indicate the name of the tool used or the state you operate out of.	Open-ended

Abbreviation: ADS, adult day services.

The medical management domain covered common clinical concerns in older adults. Six of ten states assessed for presence of constipation and five assessed for routine use of pain medication. Two of ten states screened PLWD for pain or shortness of breath. Use of antipsychotics by PLWD was routinely assessed by only one state. Importantly, reporting incidence of falls was only required by half of states (5/10), although falls may be recorded by the majority of ADS centers as part of their agency-level processes. None of these states reported the use of restraints or whether the client's family member would get help for their loved one's clinical symptoms (e.g., pain, shortness of breath, constipation, and anxiety or sadness). Additionally, seven states reported diagnosis and clinical assessments and five states reported skin assessment of their ADS clients.

The supportive and therapeutic environment domain evaluated the degree to which emotional support and timely care were provided to PLWD and their caregivers. Data in this domain were rarely collected by ADS within regulatory documents, though some states had measures that reflected PCROs in this domain. For example, North Carolina reported trying to engage family caregivers in the care plan by asking the clinician's "personal concerns and knowledge of the caregiver that may have an impact on the participants' care plan."

The transition and coordination of services domain measured health care use by PLWD by reporting their intensive care unit, emergency department, and hospital admissions and days. Six of ten states covered some levels of health care use, which included data on PLWD's discharge to the community, emergency department admissions, hospital admissions, and number of days in a hospital. California and New York covered the greatest number of items related to use. In addition, seven states included special needs and treatments (e.g., therapeutic activities, suctioning, oxygen, chemotherapy, dialysis) in their ADS report forms.

Compared to other domains, the assessment and care planning domain was rarely reported. None of the ten states reported items related to team communication and care delivery. Notably, only

Oklahoma reported treatment preferences for advanced care planning. Meanwhile, seven states asked ADS centers to document their clients' social backgrounds (e.g., social determinants of health, medical providers, caregiver assessment) and nine states documented nutrition information.

The information, education, and support domain was missing across current ADS report forms. Similarly, the staffing domain is not reported in Table 2, as there were no sample PCRO Library items available in this domain for the research team to look for in states' ADS regulatory documents.

5 | DISCUSSION

The current study had three primary aims: (1) to identify which states are required to regularly collect outcome data in ADS, (2) to determine which data are being collected, and (3) to examine whether and how these data align with established PCRO) in dementia care. In terms of the first aim, results from a national survey revealed that only 10 states (or 20% of all states) were required to regularly collect outcome data in ADS. Given the recent calls for increased uniform data collection in ADS,^{12,14} this result was anticipated yet the implications of this result merit discussion. The lack of regular outcome data collection hampers our ability to understand the impact of ADS on the individual, programmatic, and industry levels. On the individual level, ADS programs that don't collect data regularly are unable to accurately evaluate change in ADS participants, both improvements and declines. Such information is critical to proactive, coordinated care and essential for primary care providers who may only see PLWD annually or episodically in response to acute conditions.¹⁷ On the programmatic level, the lack of regular outcome data collection prevents many ADS centers from effectively evaluating (or having researchers evaluate) the activities and services that they offer. This programmatic problem translates into a problem on the industry level as researchers and national organizations (e.g.,

TABLE 2 Patient and caregiver relevant outcomes within the dementia care practice recommendation domains collected in 10 states

Domains	Items	CA	NY	MD	NC	NV	TX	VA	OK	KY	FL
Detection and diagnosis	Cognitive function		X	X	X		X	X	X	X	X
Ongoing care for dementia-related behaviors and activities of daily living	Urinary incontinence	X	X	X			X	X	X	X	X
	Ambulation	X	X	X	X	X		X	X	X	X
	Bathing	X	X	X	X	X	X	X	X	X	X
	Dressing (upper and lower body)	X	X	X	X	X	X	X	X	X	X
	Toileting	X	X	X	X		X	X	X	X	X
	Transferring/transportation	X	X		X	X			X	X	X
	Accessing resources	X									
	Hygiene	X	X	X		X			X	X	
	Meal preparation	X	X	X	X				X	X	X
	Medication management	X	X	X	X		X	X	X	X	X
	Money management	X	X		X			X	X	X	X
	Housework		X	X	X	X	X	X	X	X	X
	Phone use		X	X	X			X	X	X	X
	Bed mobility		X							X	
	Feeding or eating	X	X	X	X				X	X	X
	Shopping		X		X			X	X	X	X
	Self-care discharge goal										
	Hearing and vision ^a		X	X				X	X	X	X
	Assistive devices ^a	X							X	X	X
	Behavioral symptoms		X	X			X	X	X	X	X
	Wandering		X	X			X	X	X	X	X
	Presence of restlessness or agitation		X	X					X	X	X
	Presence of anxiety or sadness		X	X				X	X	X	X
	Depression		X	X				X	X	X	X
	Potential indicators of psychosis					X				X	X
Assessment and care planning	Treatment preferences								X		
	Team communication ^b										
	Discussion of problems ^b										
	Social backgrounds ^a	X		X	X			X	X	X	X
	Nutrition information ^a		X	X	X	X	X	X	X	X	X
Medical management	Presence of constipation	X	X	X			X	X	X		
	Presence of shortness of breath			X					X		
	Pain screening and assessment		X	X							
	Pain medication	X	X	X	X			X			
	Uses of antipsychotics		X								
	Falls		X			X			X	X	X
	Family members' getting help for symptoms ^b										
	Restraints ^b										
	Diagnosis and clinical assessments ^a	X	X	X	X				X	X	X
	Skin assessment ^a			X			X		X	X	X

(Continues)

TABLE 2 (Continued)

Domains	Items	CA	NY	MD	NC	NV	TX	VA	OK	KY	FL
Information, education, and support	Off hours communication ^b										
Supportive and therapeutic environment	Providing emotional support								X		
	Getting timely care										X
	Beliefs and values								X		
	Treating family member with respect				X						
Transition and coordination of services	Discharge to the community	X	X								
	ICU days ^b										
	ED admission	X	X						X		X
	ED admissions not leading to hospital admission	X	X								
	Hospital admissions	X	X					X	X	X	X
	Hospital days	X	X						X	X	
	Special treatment needs ^a	X				X	X	X	X	X	X

Abbreviations: ADS, adult day services; CA, California; ED, emergency department; FL, Florida; ICU, intensive care unit; KY, Kentucky; MD, Maryland; NC, North Carolina; NV, Nevada; NY, New York; OK, Oklahoma; TX, Texas; VA, Virginia.

^aItems not being reported in other settings (e.g., home care and hospice care) but by ADS.

^bItems reported by other settings but not in ADS.

NADSA) are largely unable to make definitive statements about the effectiveness of ADS. In turn, the lack of uniform data collection and the resulting lack of reliable data impedes efforts to draw attention to ADS on the policy level and to leverage additional funding.

Examining the actual data being collected by these 10 states, results revealed that the vast majority of outcomes centered on the physical condition of participants and reflected a medical model of care for older adults. For example, the majority of the 10 states regularly collected outcome data on physical functioning, diagnosis, behavioral/psychological deficits and dysfunction, and medication management. These data are certainly appropriate and useful in the care of older adults, including those with AD/ADRD. Changes in physical functioning, for instance, are an important indicator of disease presence (e.g., stroke) and progression and the need for follow-up care from primary care providers. In addition, effective medication management can reduce medication-related problems that can result in emergency room visits and hospitalizations.¹⁸ While these data can be useful, most ADS centers reported the use of non-standardized measures and scales. A lack of data is problematic, but the use of non-standardized measures and scales and the resulting “bad data” may be worse than having no data at all. Unreliable data can lead to policies and decisions that are inaccurate, ineffective, and illogical. It is notable that very few or, in some cases, none of the 10 states reporting regular data collection included domains related to care planning and coordination, education, social support, and/or family caregiver burden and support. These are key functions of home and community-based services and such services “can decrease unnecessary medical services utilization, delay institutionalization, and improve the quality of life of both patients with ADRD and their caregivers.”¹⁹ This is not to say that ADS centers do not provide these services; rather, they may not be reporting this data. Indeed, socialization and social support are defin-

ing elements of ADS and caregiver respite has been found to be one of the more effective services offered by ADS centers.²⁰ ADS would be well served to focus on these outcome domains as the resulting data could paint a more complete picture.

5.1 | Operationalizing the dementia care practice recommendations in ADS

Finally, the researchers reflected on the outcome data being collected in ADS, and how these data align with PCRO Library items within the DCPR domains identified as being important to dementia care. As illustrated in Table 2, Oklahoma (69.8%), New York (64.2%), Kentucky (60.4%), and Florida (58.5%) had mandated data collection outcomes that aligned with approximately two-thirds of PCRO items in the DCPR domains. The remaining six states aligned with approximately half or less than half of the DCPR domains. Once again, it should be noted that only 10 states or 20% of all states reported any PCROs.

Several content areas and items within these domains that were either not measured or only measured by one state stand out as they are services that either are provided or could be provided by ADS. Advance care planning/treatment preferences and communication refers to discussing and identifying care preferences and decisions regarding treatment of illness in late-stage and end of life stage. Researchers have identified communication as the key contributing function leading to “the uptake of ACP (advance care planning) among older adults.”²¹ Advance care planning is typically a process that requires ongoing discussion and thought. Given the fact that older adults usually attend ADS over the course of months and years, ADS is an ideal setting for the process of establishing advance care planning. ADS centers could easily add this an outcome using a simple

measure of “yes/no.” Alternatively, ADS centers could use the Centers for Medicare and Medicaid Services Merit-Based Incentive Payment System (MIPS) measure of advance care planning that records the number of individuals with documented advance care plans and surrogate decision makers or that advance care planning was discussed but not established (i.e., participants engaged in the process).²²

Providing emotional support is a content area/item that was only measured by one of the ten reporting states. Undoubtedly, every ADS center provides some degree of emotional support to participants and family caregivers, especially for those impacted by the emotionally draining condition of AD/ADRD. Emotional support could easily be measured in ADS using measures such as the 4-item perceived emotional support subscale from the patient-reported outcomes measurement information system.²³ An example item reads, “I have someone who will listen to me when I need to talk.” In sum, it appears that ADS is missing opportunities to measure outcomes in domains in which they currently address and in domains in which they could easily extend their services in dementia care.

This study is certainly not without limitations. First, we relied on results of a previously conducted national survey to help us identify states that mandated participant-level data collection at ADS sites. In that survey, 14 states were not represented. It is important to note that some of the states that were not represented, such as Idaho, do not offer ADS as a Medicaid benefit. However, it is possible that other states that reimburse ADS through state Medicaid programs and do mandate standardized data collection were not reflected in our results. It is important to note, that, to our knowledge, there is no existing data repository that summarizes regulations in ADS surrounding data collection or regulatory requirements across states. Thus, while not without limitations, this study represents a novel contribution to our knowledge on data collected in ADS. Second, our methodology aligned with that used by the IMPACT Collaboratory’s PCRO library to categorize PCROs in long-term care. While the Collaboratory’s PCRO core is designed and led by experts in the field of measurement in AD/ADRD, they acknowledge that the library is not yet comprehensive and still evolving. However, it represents one of the few resources that has synthesized evidence on clinical outcome assessments relevant to persons with dementia. Furthermore, the expert members of the PCRO core selected the outcome measures based on their relevance to the lived experience of PLWD and their caregivers.

6 | CONCLUSION

ADS represent a growing and cost-effective model of community-based care for PLWD and their caregivers. Person-centered care is often touted as one of the hallmarks of ADS, yet we know very little about the impact of ADS on PCROs. Unfortunately, the findings from the present study indicate that only one in five states mandate the collection of outcome data in ADS. Among these 10 states, data collection is largely focused on physical outcomes rather than key PCROs such as care planning, emotional support, communication, and education. Rather than viewing this as an indictment of ADS, these find-

ings strongly suggest opportunities for ADS to measure and report on PCROs that are well within the reach of their services. The future of ADS (and the funding of ADS) lies in establishing evidence of the effectiveness of this service model, particularly in terms of outcomes that are important to care recipients and caregivers, as well as health-care systems. We may find that one state takes the lead in this effort of uniform, comprehensive outcome data collection, ultimately with the hope that other states follow suit.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

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